

care & connect

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The Sydney West Cancer Network newsletter

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The Sydney West Cancer Network is a collaboration between cancer services in western Sydney, which aims to improve the range and quality of services available. It includes the Blacktown Oncology Centre, Mt Druitt Palliative Care Unit, Nepean Cancer Care Centre, Westmead Cancer Care Centre and the Westmead Institute for Cancer Research.

Patients' care and experiences of treatment have been greatly improved by the Sydney West Cancer Network's commitment to multidisciplinary care.

The Network's director, Professor Paul Harnett, says patients may not be aware of the advantages offered by the multidisciplinary team meetings that have developed in recent years.

When patients' cases are presented at these meetings, it means their care benefits from the input of a wide range of expertise and opinions, he says.

"It also means that patients don't have to travel to multiple appointments," Professor Harnett says.

"These meetings are also improving the training of our next generation of cancer specialists. Our registrars are learning from multiple specialties, gaining a broad understanding of best practice in patient care."

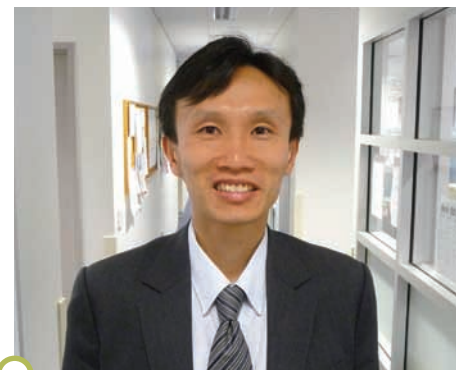
Dr Vincent Lam, a surgeon at the Westmead Cancer Care Centre, has recently helped set up a multidisciplinary team meeting for patients with liver and upper gastrointestinal tract cancers.

"It is really like a one-stop shop of experts," says Dr Lam. "It helps relieve the anxiety for patients who otherwise can face significant waits to see specialists. These teams are about putting patients first."

Robyn Daniel, care coordinator for lung cancer patients at Nepean Hospital, says the meetings also help streamline communication for patients. Instead of having to see multiple doctors, one person is responsible for telling them about the outcomes of the multidisciplinary meetings.

• **For more news about the Nepean team, see Team Focus on page 4.**

We welcome your comments on the newsletter and suggestions for stories. Our contact details are on the back page.



Dr Vincent Lam

director's message

Health in our hands

By Professor Paul Harnett

Providing the best possible service for our patients requires many things. It means staying abreast of the latest developments in research, treatment and care.

It means treating our patients with compassion, dignity and respect, and understanding their needs.

And it also means paying attention to an old-fashioned virtue like cleanliness. No matter how high-tech our services become, we must never forget the importance of hand washing.

It is essential for preventing the spread of infections between patients, visitors and staff. This is important in any health service, but particularly for cancer patients who can be prone to infections.

But even people with the best intentions can sometimes forget to do the right thing.

Dr Lucinda Morris, a resident who has been working with me and is about to join the head and neck cancer team, has been involved in auditing our hand-washing practices.

She has been observing staff and visitors and recording whether they are washing their hands before and after patient contact and when entering the wards. Her findings are fed back to unit managers and used to highlight areas for improvement.

Dr Morris tells me that generally most people do the right thing, but there is always room for us all to do better. Visitors, in particular, may not always appreciate the importance of washing their hands before and after visiting patients. This is also an important message for those caring for patients at home.

You may have noticed the bottles of antiseptic hand wash around the wards. We encourage everyone to make good use of them.

• **Professor Harnett is director of the Sydney West Cancer Network and a medical oncologist at Westmead Hospital.**



Professor Paul Harnett

network news

Celebrating 20 years of looking good

It was time for cake and cheer when celebrations were held in May to mark 20 years of the Look Good, Feel Better program at Westmead Hospital.

Ms Louise Maher, a nurse and a care coordinator for breast cancer patients, has been involved with the program since its inception, and says 3600 women have done workshops at the Westmead Cancer Care Centre.

The workshops teach techniques that help people with cancer adjust to their appearance and self-image changes as a result of chemotherapy and radiotherapy.

"There is generally lots of laughter at the workshops," says Ms Maher.

"It's a really fun, light-hearted event. By looking good, women can start to feel better, which enhances self-esteem, a positive attitude and emotional well-being."

Look Good, Feel Better workshops are held at Westmead Cancer Care Centre every two months. Workshops for men and adolescents are held at other venues.

• For more information and to register, visit www.lgfb.org.au or call: 1800 650 960

a patient's journey

Taking control of treatment side effects

For Elizabeth Horn, the worst part of having breast cancer was not the diagnosis or the treatment, but a side effect – lymphoedema.

Lymphoedema can occur after surgery for cancer. If lymph nodes have been damaged or removed, the lymph fluid may not drain properly, causing fluid build-up and swelling in some parts of the body, especially the arms and legs.

“The cancer was upsetting, but once I finished the chemo it was all finished,” Elizabeth says. “The lymphoedema has gone on and on, and it’s a disability, but with the right help it can be overcome and you can lead a normal life again.”

“ I can cope with the lymphoedema quite well now ”

Elizabeth developed lymphoedema after surgery in 2004, in which lymph nodes were removed for testing. With her left hand and arm blowing up like a balloon, Elizabeth worried she might not be able to do the things she loved, such as cooking, sewing and machine knitting.

She was referred to Penrith Lymphoedema Clinic, where occupational therapist Georgette Danyal bandaged her arm to help reduce the swelling.



Elizabeth Horn at her knitting machine

She later measured Elizabeth for a pressure sleeve that was made to measure in Germany and which Elizabeth wears every day.

“I can cope with the lymphoedema quite well now, but in the beginning I didn’t know what was going to happen,” Elizabeth says. “Now I forget that I’m even wearing the sleeve.”

Elizabeth says Georgette was wonderful, providing not just technical expertise but emotional support when she was at her lowest ebb. Elizabeth’s message to other people is that lymphoedema can be controlled.

“I hope the Penrith Lymphoedema Clinic will always be there,” Elizabeth wrote in a thankyou letter to Professor Paul Harnett at Westmead Hospital. “I, and many others, find it indispensable.”

practical tips

Preparing for a stay in hospital

You want to be as comfortable as possible during your stay, so make sure to pack sleep and casual wear that is not too tight. You don’t need to wear pyjamas if you find tracksuits more comfortable.

Make sure your slippers have rubber soles to reduce the risk of slipping if you are feeling weak or unwell, advises Katherine Cox, the nursing unit manager for oncology and palliative care.

She also recommends bringing something to help keep you occupied, whether magazines, puzzles or a good book. Many patients like to bring photographs and other reminders of their loved ones.

These days, it is quite common for patients to bring in laptops, although the staff cannot take responsibility for the security of private items.

Ms Cox says the average length of stay is around one week, although one patient recently went home after 65 days on the ward.

And one last thing – whatever you bring to hospital, don’t forget to take it home. The ward is developing quite a collection of mobile phone chargers, says Ms Cox.

team focus: lung cancer

Working as a team for better outcomes

Every Friday morning, an important meeting takes place at Nepean Hospital.

A multi-skilled team of health professionals who treat lung cancer patients meets to discuss the management of new patients and to review the care of existing patients.

These meetings are usually attended by more than 15 experts, and mean that patients benefit from a range of opinions.

Dr Peter Flynn, a cardiothoracic surgeon, says the Nepean lung cancer team was one of the first cancer services to introduce such a systematic approach to multidisciplinary cancer care about 15 years ago.

The team reviews about 120 to 130 new patients a year.

Dr Flynn says research has shown that the Wentworth area has higher-than-average lung cancer survival rates. He believes this reflects the benefits of the multidisciplinary approach, as well as the team's early adoption of new treatment techniques.



Dr Peter Flynn and lung cancer care coordinator Robyn Daniel

"The Nepean lung cancer unit has outcomes among the best in Australia and prides itself on being innovative and at the forefront in lung cancer management," he says.

Nepean Hospital was at the forefront of introducing a radiotherapy technique that enables more precise delivery of radiation by timing its delivery to patients' breathing.

This "gating" technique minimises the damage to the healthy lung. More recently, it has also been introduced at Westmead Hospital, under the guidance of Nepean staff.

Where science meets patient care

As a researcher, Dr Rosemary Balleine has spent much of her career investigating cancer in the laboratory.



Dr Rosemary Balleine

But she is gaining a new appreciation of the potential for science to improve patient care thanks to an innovative collaboration with the lung cancer team at Nepean Hospital.

Dr Balleine, who is based at the Westmead Institute for Cancer Research, recently began attending the team's weekly multidisciplinary meetings.

The aim is to encourage an exchange of information. First-hand experience of clinical issues helps inform her research, and gives her a better understanding of the questions that need answering.

"It's a real-world way of formulating research questions," Dr Balleine says.

Her research background can also give the lung cancer team useful insights into the care of patients. Dr Balleine is finding the collaboration enormously productive.

"The Nepean group is very active and forward looking in their approach to managing their patients," she says.

"It must be a positive thing for the patients to think that they are being cared for by a team that is actively seeking answers to the unanswered questions and seeking new knowledge."

getting to know us

Helping people to grieve in their own way

Kristin Westman gives people a chance to talk about their grief at a time when many people are expecting them to “get over it”.

As palliative care bereavement counsellor with Sydney West Area Health Service, Kristin’s role is to help people understand grief and their own reactions, and to explore ways to cope.

For many people, simply realising that their feelings are often normal is a huge relief, Kristin says.



Kristin Westman

Kristin’s suggestions for supporting a bereaved person

- Understand that grief is unique – and that people grieve differently.
- Give people space to grieve in their own way. Be there for them and offer practical help so they can manage their emotions.
- Recognise that grief doesn’t have a set time limit or occur in stages. It is often chaotic and can be triggered months or years down the track.
- Support people to seek help if, over time, their grief seems to worsen and affects their day-to-day life and relationships in a significant or damaging way.

“A lot of people feel pressure from family and friends to ‘move on’, so bereavement counselling can normalise grief as a reaction to a really significant and difficult life event.”

As well as helping individuals, Kristin is passionate about developing awareness so that people are under less pressure to grieve in a certain way or for a certain time.

“The way that society approaches grief sometimes can be really damaging for bereaved people,” she says. “It’s an ongoing challenge to promote a healthy approach to grief.”

While grief can be difficult and painful, Kristin says that through her work, she also witnesses the richness of human experience. “It’s a privilege to be allowed into people’s lives,” she says.

- ***Bereavement counselling is a self-referral service that is open to family, carers and friends of someone who has died and was known to the Palliative Care Service or linked with a Palliative Care Community Nurse in the Eastern and Central Clusters of SWAHS. For more information, call 9881 1695.***

question corner

Q My doctor asks about what vitamins and over-the-counter medicines I’m taking. Why is that important?

A If you are being treated for cancer, it’s important to tell your doctor about any medicines or pills you are taking, including vitamins, dietary supplements, medications (prescription and over-the-counter), and complementary and alternative medicines — even if you think they are harmless. This is because some pills and medications interact with cancer drugs and cause side effects or stop them from working properly.

So the best advice is to tell your doctor about everything you are taking, and to not start on any vitamin, supplement, or medicine — herbal or otherwise — without first talking to your doctor.

- ***For more information, talk to your doctor about this.***

news & views

Caring for the carers

People who care for cancer patients need more support to help them cope with the increasing demands they face, according to an expert in palliative and supportive care.

Professor Anne Wilkinson, of the Western Australian Centre for Cancer and Palliative Care at Edith Cowan University, analysed the studies of cancer caregivers published between 1990 and 2010.

She found that carers had complex responsibilities, including nursing care, managing symptoms and medications, transporting patients to appointments, coordinating care, and being an advocate.

She said family carers regularly reported feeling unprepared for and “overwhelmed” by their responsibilities, particularly when providing end-of-life care.

The needs of carers were often neglected or under-appreciated, she added, and more attention should be paid to reducing their burden, stress, anxiety and burnout.

“There is an urgent unmet need for innovative solutions to the challenges involved with providing high-quality, compassionate care to the terminally ill and their carers,” she said.

The article was published in *Cancer Forum*.

Family history matters

The importance of family history is often neglected in medical consultations and deserves more attention, according to a recent editorial in the *Medical Journal of Australia*.

The editorial was commenting on an audit of medical records that found almost three-quarters of short-stay patients admitted to a Perth hospital did not have any details of their family medical history recorded.

The editorial said it was time to make better use of patients’ family history, which may help with diagnosis and assessing risks for disease, as well as provide valuable insights into patients’ situations.

“Internationally, there is growing recognition that a family medical history can support

tailored disease prevention, which may be more effective than existing approaches,” the editorial noted.

It said there was evidence that people who knew their family history might be more inclined to take up activities that could prevent diseases such as breast, colorectal and skin cancer.

Behind the headlines: do household cleaners really cause cancer?

Earlier this year, there were widespread media reports about a study that showed “houseproud women with spotless bathrooms could be twice as likely to get breast cancer”.

How seriously should we take these reports?

It’s way too early to throw out your cleaning products, says a review of the study.

The US study, published in the journal *Environmental Health*, asked women with and without breast cancer about their use of household cleaning products.



It found that women with breast cancer were more likely to recall using cleaning products more frequently than women without the disease.

But the review found the study’s findings were affected by “recall bias”, meaning the breast cancer patients may have remembered using cleaning products more than they actually did.

The relatively small number of women in the study also meant the findings could not be considered conclusive.

The bottom line, the review said, was that more research was needed to see if there was an association between breast cancer and cleaning products.

The review was done by Behind the Headlines, a web-based service provided by the National Health Service in Britain to make sense of media reports of health and medical news.

guest appearances

Training the next generation of doctors

By Professor David Harris

Medical students need to acquire a lot of knowledge to become a doctor, but the most important aspect of their training – interacting with patients – can't be learnt from a textbook.

It's vital that medical students spend a lot of time with patients – both to develop the skills they need to interact and communicate with patients and also to learn how to examine a patient and take their history.

At Westmead Clinical School, there are about 60 University of Sydney medical students in each of the four years of the course. Students spend more and more of their time involved in clinical teaching as their course progresses, gaining independence along the way.

In years 1 and 2, students are at Westmead Hospital one day a week, to learn skills in ward-based tutorials with senior doctors. They also spend two full-time eight-week rotations at Westmead in haematology (year 1) and medical oncology (year 2).

In years 3 and 4, students spend all their time at hospital or in the community, doing rotations in medicine, surgery and other specialties. They are part of the medical team and tag along with residents, registrars and senior consultants, constantly interacting with patients and learning.

Of course, all this on-the-job training couldn't happen without patients.

As patients in hospital are often very sick, it is understandable that they may not feel like seeing a medical student. It is a patient's right not to see a medical student and we all respect this choice.

However, most patients recognise the importance of training young doctors, whether for their own care or for future generations, and we are grateful for their generous co-operation.

- **Professor Harris is head of Westmead Clinical School.**



Professor David Harris

connections

The Leukaemia Foundation is one of the many organisations that support cancer patients in western Sydney.

The Leukaemia Foundation works in many practical ways to help the people of western Sydney, through providing transport, accommodation, information and emotional support.

The Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemia and other related blood disorders.

In western Sydney, as in other areas, it works at the local and community level to help patients and their families.

The Foundation has an office near Westmead Hospital, which coordinates services, including a free service that takes patients to and from medical appointments.

It also has accommodation for patients and carers near Westmead Hospital and the Children's Hospital at Westmead. The six two-bedroom apartments are self-contained and have on-site care from support services staff.

As well as this local practical support, the Foundation offers education programs and support groups for patients and carers.

With around 600 people diagnosed with leukaemia and other related blood disorders in western and south-western Sydney each year, the Foundation's work is vital for the patients and staff of Sydney West Cancer Network.

- **For more information visit:**
www.leukaemia.org.au

useful resources

New website helps reduce risk

How healthy is your lifestyle, and what can you do to reduce your cancer risk? Cancer Council Victoria has launched a new website that can help you and your family answer these questions.

<http://cutyourcancerrisk.production.cancervic.org.au>

Helping the children of cancer patients

My Parents Cancer is a website to help young Australians aged 13 to 19 who are coping with having a parent or parents with cancer. The website, produced by the National Breast and Ovarian Cancer Centre, might help parents understand some of the common issues facing young people in this situation.

<http://www.myparentscancer.com.au>

A reliable source of information

With so much misleading health information on the Internet, it pays to know which information sources are reliable. Dr Catherine Mason, director of psycho-oncology at the Sydney West Cancer Network, recommends the website of the Memorial Sloan-Kettering Cancer Center. Although it is a US institution, much of the general information is relevant to Australians.

<http://www.mskcc.org/mskcc/html/457.cfm>

help support our work

All donations received through **Care & Connect** will go directly to Sydney West Cancer Network to support patient care, research, equipment and community education.

To donate you can:

- Donate online at www.wmrf.org.au
- Post cheque or money order to:

C/ Westmead Cancer Care Centre
Westmead Medical Research Foundation
PO Box 74 Westmead NSW 2145 *or*
- Ph 1800 639 037

contact details

Telephone: (02) 9845 5555

Patient Enquiries: (02) 9845-6588
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